

COMMUNICATING TOGETHER

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Parenting

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In planning this issue, we began with the need to say more about sexuality and the desire to focus upon the theme of parenting - both of and by AAC users. Three articles by parents of AAC users speak ably about both the importance and the complexity of parenting a child with disabilities. Although selecting one of them for the feature was difficult, we finally decided on *Integrating Nicholas: Education is the Goal* by Lou and Leslie Baker. We realize however that Ruth Harrington's *Parenting: And Then Some* and Joseph Creech's *Parenting in the Fifties and Sixties* offer equally valuable insights.

We are fortunate this time to have material for two **Perspectives**. One of them provides the perspective of an individual with disabilities who is raising a teen-aged daughter — Gabriela Brimmer's *Finding her Way*. We have included a very powerful poem by "Gaby" which amply demonstrates that her inability to speak has not dampened her passion for life or her awareness of the world around her. Joe Creech on the other hand in the second **Perspective** provides the perspective of an able bodied parent raising an child with disabilities —his son Rick. In fact we had hoped that his son Rick would write about his parenting experiences since he is raising three children of his own. Unfortunately however Rick was just too busy with completing his thesis as well as raising his children. He promised to contribute to a future issue.

Cheryl Bedard and Lillian Burke continue the discussion of sexual abuse of individuals with physical disabilities that was introduced by Susan Webber and Sachi Tamura in our March issue. Cheryl and Lillian rightfully urge increased sexuality training for both AAC users and their caregivers.

Once again, Geb Verburg challenges our thinking. He looks to the future where disabled persons will set their own goals and priorities. He talks of the dissatisfactions consumers have with the present consumer-professional relationships, that some of our service delivery systems have become separated from the daily realities of their clients' lives and that many disabled persons feel they are not allowed to take control of their own lives to-day? This shifting in roles places increased demands on parents and professionals alike. In the future, they will have to provide the increased knowledge their children will need, for without that knowledge, their empowerment will be but an empty shell.

The New Empowerment

"Health is not the absence of disease but control over your life" (quoted by Audrey King)

"Consumers should have the right to behave as absurdly as everyone else" (Alice Loomer)

"We (parents and professionals alike) must remove the passive roles of consumers through empowerment via education - only an informed consumer can make an informed decision" (Gina Osborne)

"Yes but how do I know when I should encourage the person because 'I know what's good for them' versus 'I am not listening'" (The question of a perplexed but highly moved engineer)

All of the above quotes came from an exciting short course on *Technol-*

ogy, Ideologies of Care and Consumer Empowerment, organized by Geb Verburg prior to the RESNA International '92 Conference in Toronto in June. The course title really did little to alert us to the treasure of information that we were to receive and the moving experience it would be. All four speakers were excellent: Gina Osborne, Alice Loomer, Karin Paulsson and Audrey King. We hope you'll be hearing from some of them in the pages of **Communicating Together** in the future. However it is Gina's point of view we would like to share with you now. Her insights as a very capable and sensitive parent who, over the years has raised over 20 children with disabilities ably presents the perspective we would like this issue of **Communicating Together** to portray.

Given the topic for the short course, Gina focused on the consumer and technology. Many of her comments and recommendations as a parent however, can be applied to all aspects of the child's life. She advocated teaching even very young children to speak out about their needs so that they will learn *to expect to be a partner* in decision-making and not to accept someone else telling them that they know "what is best for you". Parents should champion the client and family needs without guilt. Professionals should recognize and respect a consumer's individual needs holistically (family, home environment, cultural, religious values). Best of all, for consumers to move from a "passive" role to a truly collaborative one, the key is education (hence her quote above —only an informed consumer can make informed decisions).

Her personal experiences very often hit a responsive chord with those in the audience: "Specialists talk about

you to other specialists as if you aren't even there!" "You only see the catalogues with information they want you to see." "You get a blue wheelchair or a certain model because that is what everyone is getting these days." "Those who are developing equipment for a child should come and live with the family for a week!" Gina suggested a provocative scheme for informing developers - "Adopt a researcher!". Her emphasis upon recognition of individual differences and giving the individual choices did these two educators' hearts good! Oh, that all parents could advocate for their children so eloquently.

We hope this issue of **Communicating Together**, with its examples of the initiatives and changes parents are making will stimulate letters from other parents. It is important to share the impact parents can have and along the way provide the information which will allow others to undertake the much needed advocacy and activism. Until children are ready to assume the responsibility for and control over their own lives that is more and more being sought by those with disabilities, parents need to support and educate them and show the world what their children can do.

Communicating Together in a New Format

In an attempt to make **Communicating Together** accessible to those who are unable to read, we are considering the production of sound tapes which will provide summaries of the articles of each issue. The cost of receiving the tapes would be \$15.00 Canadian in addition to the individual's regular subscription fee. To help us in our decision-making, we would welcome hearing from those who would wish to obtain **Communicating Together** in this additional format.

"Oops!"

We regret we were unable to receive formal permission to print the excerpts from the writings of the AAC users quoted in our March editorial prior to publishing. We have since requested such permission and have received it for the quotation from **The Troubled Bush** by Earl Schenck Miers from his wife Starling. In fact we were so delighted with Mrs. Miers'

response that we have included the letter in our Readers Write. We have also permission to publish the excerpt from **My Left Foot** by Christy Brown. It has been reprinted with permission of Martin Secker & Warburg Ltd.

We are also sorry that we omitted the acknowledgement statement which should accompany the publication of **Blissymbols**: Blissymbols used herein derived from the symbols described in the work, **Semantography**, original copyright C.K. Bliss, 1949; Exclusive licence to the copyright, Blissymbolics Communications International, 1982.

Rate changes

We are very gratified to have had a small but real increase in the number of subscribers to **Communicating Together**. Thank you to all who helped spread the word. Even with the increased circulation and all of the volunteer labour that goes into this magazine however, we are still unable to cover the costs at the old subscription rates. As a result we have reluctantly had to increase our rates by an average of \$2.00 per year.

Next Issue

In September, we look forward to the theme of Independence, Interdependence, Dependence and Socialization. We urge you to send us your thoughts on the September theme or your reactions to our March and June issues.

COMMUNICATION OUTLOOK

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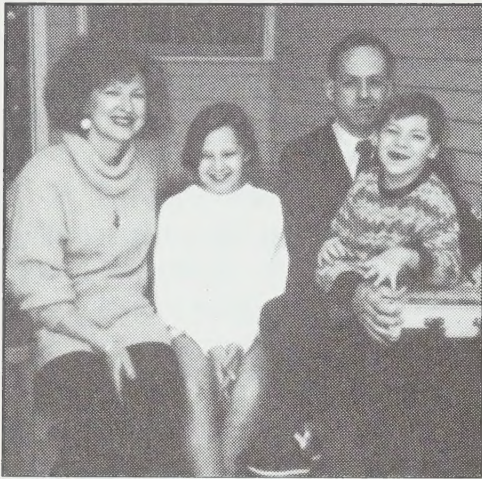
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INTEGRATING NICHOLAS: EDUCATION IS THE GOAL

LOU & LESLIE BAKER



Lou and Leslie Baker live in Wilmette, Illinois, a suburb of Chicago. Their two children, Vanessa (age 11) and Nicholas (age 9) attend public schools. In the fall, Vanessa will enter 7th grade; Nick will be enrolled in 4th grade.

Nick is physically disabled and uses a Prentke Romich TouchTalker™ for speech. Leslie is a certified teacher with experience in education and business. She has recently returned to the field of education in a consulting capacity. Lou is a lawyer who, after 18 years with large corporations, has established a private practice concentrating on disability law.

*We first met the Bakers at a conference on literacy and AAC in North Carolina. We were so delighted with their presentation at the conference, that we asked them to contribute an article to **Communicating Together**.*

As Nicholas rolled up the sidewalk toward the door of the neighborhood elementary school, he must have had strong feelings of anticipation about going to a regular school and about being included on the roster of the regular third grade

class. We, as parents, had feelings about this event also. Part of it was a sense of pride in our son's evolving ability to demonstrate his skills as a learner. Part of it was a sense of accomplishment after six years of almost daily struggle to persuade, plead, demand, threaten, outguess, and out manoeuvre the "opposition." Our victory celebration had been a private and quiet one, as we contemplated the greater challenges that lay ahead of us.

Making the Regular School Accessible

The most immediate of the challenges we faced was how Nicholas would get to the second floor classroom in a building that had no elevator. The first day of school we carried Nick, his wheelchair, his walker and his TouchTalker™ up and down the stairs. Then we kept him at home for two weeks while we reasoned with the administration. Finally, we announced that we were coming back to school and either they could have accessible space ready or we would create the space ourselves. For the next two months, Nick used the cafeteria as a classroom. Once again, he was isolated with just his teacher, his aide and the instructional materials prepared by his mom. A chair lift installation was only a possibility—if there was money left over after paying for an environmental cleanup project (buried fuel oil storage tanks). The system procrastinated. The lift was installed three weeks after Lou was elected to the local Board of Education.

Checking on the progress of the lift installation was easy compared to the other requirements that had to be met if Nick was to be able to stay at school. There were lesson plans to

prepare, materials to purchase and make ready, programming of the TouchTalker™, meetings with teachers and staff. People have asked us how parents can do all this and why they should be expected to do so. Is it worth the effort? We will continue to do the work and would gladly repeat the six year campaign because we gained two things. First, our son has "escaped" from an oppressive special education environment. Second, we have (at least for the moment) gained control over his program.

Parents in the School

Are parents really welcome at school? Doesn't a close involvement such as ours invite chaos in the school system? What if every parent wanted to customize their child's program? We believe we have been able to give direction to this program because we have patiently and persistently demonstrated the shortcomings of the school-provided programs, and we have offered a rational alternative that had a chance for success without extraordinary cost. Parent involvement is justified because it is traditional in the United States for the parents, directly or indirectly, to have the final say in the upbringing of the child.

Nick's Early Years

Before talking more about his school program, let us tell you a bit about our son Nicholas. Nick was born in 1982 and showed normal development. At eleven months, he became ill (later diagnosed as encephalopathy), experienced a three-day coma and has ever since been without functional speech. He uses a wheelchair in school, at meals, and for travel. He exercises

with a walker for long distances and has fine motor skills sufficient to operate a TouchTalker™ or any keyboard.

Special education started at an early age for him. He was only two when we sent him on a 90-minute bus ride to a public school program for the Physical/Health Impaired (a category defined by Illinois law). We visited the classroom to observe the program. We attended meetings where Individualized Education Plans were developed. We talked to other parents. It became clear that the children in this program were not being treated as students. A label was being used not to focus resources of expertise, but to limit opportunity. Why, we wondered, did no special education student ever "graduate" into regular education? Why was "free time" the major activity of the school day for students supposedly mainstreamed into regular academics?

There we were, living in a comfortable suburb of Chicago where people took pride in their up-to-date approach to everything, a place where 22 school districts pooled their resources to provide special education services. We had been told that this special education cooperative was the best quality, the best funded, the most progressive. We quickly learned otherwise and resolved to take responsibility for our son's future. The school reported to us that our son's disabilities were so unique that no one could help him. They stated unemotionally that his case was hopeless.

While the school staff was busy labelling our child as not educable and documenting his failures, we were busy labelling the program as expensive daycare. Students were condemned for their disabilities, rather than encouraged to develop their abilities, character, and personality. What a discouragement it was to find that no alternative programs existed.

Parent Action

Parent reactions to the situation varied. Some became angry and sued their school district and the special education cooperative. Some moved out of town, seeking a more enlightened community or at least a fresh start. Each family has to cope with these issues in their own way. We do not mean to say that one approach is better than another. We share our experience in the hope that it may offer encouragement to others. We should never be satisfied to live in a community where parents are forced to give up hope for their children's lives.

We concluded that filing lawsuits, moving, or accepting the status quo doesn't help the child. At first, we didn't know what to suggest. Lou, a lawyer did a quick study on special education law but had no credentials in teaching or medicine. Leslie, a former teacher with course work in speech and language was certified only at the high school level. We were not experts. Certainly, we were not treated as experts. We searched for sources of expertise and tried to learn as much as we could about Nick's condition. He received lots of therapy and we got lots of arguments from the insurance company.

Introducing AAC

We had an Apple, kids' software, joy sticks, Unicorn boards, AFC cards, etc. Step by step we were forming ideas of what Nick could do and what he couldn't do. One thing that we regret is that we did not discover AAC sooner. His sound production never included enough vowels to express a full range of vocabulary. He probably suffered because we waited to see if speech would develop. We delayed because logic said that if he relied on a machine, he would never try to produce the sounds himself. Logic was wrong in this case.

Finally we learned about the Prentke Romich TouchTalker™ and purchased one for Nick when he was

seven. The TouchTalker™ has been ideal for his needs. We were surprised to find that Nick learned the keyboard so easily. Using the expanded keyboard and software, he moved quickly to a full 128 location format. It is the use of this device as much as anything that we did as parents that freed Nick from a very bad school experience. The school psychologist observed Nick using his TouchTalker™ in a structured setting and concluded that a major breakthrough had occurred. The fact that Nick demonstrated that he could sequence two or three icons to express a few simple messages was enough evidence to prove that he had a mind and a personality. From that point on, our chances of changing his school program improved. School people began to think that we were on to something new and interesting.

Nicholas' Current Program

Over a two-year period we phased in Nick's program under the premise that it was experimental. We borrowed liberally from our readings of AAC literature, adding our own experience, the power of Minspeak™, and lots of common sense. From this combination, the program was designed following these principles: (1) the teaching team consists of a classroom teacher, an AAC teacher, an aide, and an AAC curriculum consultant; (2) the amount of time spent in the regular classroom varies from week to week depending on the circumstances; (3) the regular curriculum is used with modifications for the TouchTalker™ provided by the consultant; (4) a one-to-one aide trained in AAC is provided; (5) physio and occupational therapist are provided as necessary on-site or off-site; (6) speech therapy is discontinued as a separate activity; instead, it is integrated into the instructional program; (7) a study centre is created, separate from the regular classroom for use during alternative activities; (8) conven-

tional assessment techniques are inappropriate and therefore are not used.

Mainstreaming

One concept that was hard to explain to the school district was that Nick should learn the same things as the children in the regular third grade. The intention was that he acquire the same *kind* of knowledge using, as needed, alternative materials, methods, and activities, in each instance incorporating the use of his TouchTalker and Minspeak organization. This would require close collaboration between the regular teacher, the AAC teacher and the AAC consultant. For example, because Nick would frequently use an alternative format to do his mathematics, he would need to go to his study centre where resources would be arranged to suit his needs.

Why does he need this alternative approach? Because nearly everything in the conventional teaching model involves pencil and paper work, excessive rote learning, oral recitation, etc. The conventional model is based on techniques that many nonspeaking students cannot perform. Our model does appear to be rather labour-intensive. The law requires that when a student receives instruction, a certified teacher must be present. Therefore, when Nick goes to his study center, the instructional AAC resource must be a certified teacher. For administrative reasons, the work of an aide is not done by a teacher, so Nick has a two-to-one ratio much of the time. Based on our two-year pilot program, we think that the AAC teacher could handle four to six students, thereby keeping the cost at a reasonable level. Nevertheless, special education costs money and it will never be inexpensive.

The long-term involvement of an AAC specialist, whether consulting or on staff, is needed for three main reasons. First, to customize the

curriculum for each student - often a daily task. Second, to provide continuity from year to year to account for teacher changes. Third, to keep the school current with AAC developments. It is difficult to attract a teacher (or an aide) who wants to take the time and effort to learn something about AAC. If the teacher is a different person each year, why should the student wait idly while the teacher is learning the technology? Without program continuity, there is a substantial risk of inconsistent methods and ideas.

Without an organized and well supported structure, AAC will not be implemented into instruction. Inservice is not enough. The occasional consultant's visit is not enough. An AAC framework should be permanent in schools to direct resources toward learning and academic achievement. The structure should be flexible enough to accommodate individual needs and any AAC system or device.

Two observations have been made about our program. First, it is not mainstreaming because only about 15% of Nick's time is spent in the regular classroom. Second, the model is a tutoring format and must be so expensive that few school districts would approve it.

Our view is that mainstreaming is not an end in itself. *Education is the goal.* Over time Nick will probably increase his minutes in the regular classroom. Location of his desk is not important to us. We will send our son to any school, to any classroom setting where he can get his education. When a child is sent to school with an AAC device and is parked in the back of the regular classroom, what assurance is there that he/she will learn anything? As far as cost is concerned, we have to recognize that special education is more expensive than regular education. Mainstreaming is not going to make it any cheaper. Like any other

school program, even though mandated by law, special education must compete for limited monetary resources. Teachers and administrators can do their part by advocating continuous improvement in the quality of programs.

Even under the best of circumstances, parents should not rest. They must continue to be advocates for all children, not just their own. They can help other parents by sharing their experiences. Parents should make the important decisions about their child's welfare and not leave them entirely to experts. To the extent that it is possible, they should seek some control over their child's education. Most of all, parents should never lose faith in their child's ability. As parents, we must trust our instincts about our child's potential.

This is our request: Let children do what they can do. If it is a lot, we can be thankful that we helped them achieve it. If it is a little, we can be satisfied that we did not stand in their way.

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For information about the **Fifth Annual Assistive Device Conference for Students, Parents and Educators**, which will be open to persons from outside Pennsylvania, contact Colleen Haney, Pennsylvania Assistive Device Center, 150 South Progress Ave., Harrisburg, PA. 17109, USA; Phone 717 657-5840 or 800 222-7372 (toll free within Pennsylvania)

Parenting: And Then Some

RUTH HARRINGTON

*For this issue of **Communicating Together**, Ruth Harrington, Kari's mom, brings her years of experience 'And Then Some' to Learning and Living.*

In the Introduction to William Rush's book, **Journey Out Of Silence**, Bill quotes his Parents' Creed:

"This is a baby.
He needs what all babies need.
This is a child.
He needs what all children need.
This is an adolescent.
He needs what all adolescents need.
This is an adult.
He needs what all adults need.
Oh, by the way,
he has cerebral palsy."

I am tremendously impressed by how simply and directly Bill's parents have expressed the basic truth about the needs of a child who has sustained an injury to his or her brain. However, looking at this creed from my point of view as a parent, I find myself wanting to add, "And then some!" to the end of every line.

In this article, I plan to touch on some of the extra demands which I think make parenting a child with special needs different from the norm and different from family to family. No two situations are ever exactly alike. Every baby who has acquired cerebral palsy is different and each one of them must follow their own unique developmental path. In addition, the circumstances for each family and the way in which each parent is able to respond to the needs and interests of his or her child is different.

Each Family is Unique

To demonstrate the variance from one family to another, I will contrast Kari's early years with those of Joslin, a delightful three-year-old whom I met a year ago. Joslin and her twin sister, Julia, are the first children of Linda Mann and Wayne Kole. (They have just been joined by Justin, born this May.) Kari was presented to us as a healthy newborn, eligible for adoption. Joslin's very fragile condition at birth required her separation from Linda immediately after her birth for specialized medical intervention. While some parents in this situation might have received the respect, support and assurances they needed, Linda and Wayne did not. The way in which they and Joslin were treated made them feel totally powerless, excluded and frustrated. Not knowing exactly what was happening to their baby, being left out of the decision-making and being unable to contribute to their baby's comfort and well being, they experienced an emotional turmoil which was far harder to deal with than their baby's unique needs.

With Kari, it has only been in hindsight that my husband, Bob, and I have learned that the problems she experienced during her first eleven months were manifestations of cerebral palsy. We had been led to believe that she was just slower in developing and that whatever was wrong was fixable with time. Although there were very real concerns and frustrations, we were empowered to look after her and to deal with her difficulties the best way we knew how. The normal bonding had not been interrupted and our value as parents was not threatened. We had the advantage of being able to focus all our energies on meeting Kari's needs as we saw them. The ultimate unfixable

diagnosis of cerebral palsy, made at eleven months, was a tremendous shock. However, our adjustment to and acceptance of this unexpected information was supported in many ways which are not available to parents who are faced with the shattering possibility that their newborn infant may not survive.

We All Feel Disappointed

In spite of very different beginnings and the different demands made of us at that time, we parents of children with disabilities do have one thing in common. We all must deal with the disappointment we feel in not having the normal, healthy baby we expected. We somehow have to get ourselves to the point where we can accept our feelings of hurt, resentment and even guilt, and know that they are perfectly normal reactions. We must put aside all those personal and resentful feelings, along with all the difficult experiences of those early months when we first learn of our child's disabilities. When we are able to do that, we are better able to focus our energies on helping our child reach his or her full potential.

Join ISAAC Now

The International Society for Augmentative and Alternative Communication (ISAAC) offers members reduced rates for: **Communicating Together**, **Communication Outlook**, and **Augmentative and Alternative Communication** (AAC journal).

For a membership application or other information about ISAAC, write ISAAC, P.O. Box 1762, Station R, Toronto, Ontario, Canada, M4G 4A3.

We can concentrate on the pluses of this special kind of parenting. Because Kari was our adopted daughter, we were spared feelings that we were somehow responsible for her condition — feelings which are experienced by many parents, no matter how unwarranted they are.

Our way of coping

Like most parents, the first thing Bob and I did was get as much information about cerebral palsy as we could find at that time. We sought out other parents of children with cerebral palsy and joined a parents' group right away. Through this group, we visited an institution for physically and mentally impaired children in Orillia, Ontario. After that visit, we knew we had seen the absolute worst of what life could be for Kari and for children who had physical disabilities like her. For Bob and me, it was good to look at the worst possible situation. We returned home counting our blessings for all Kari's pluses and vowed we would do whatever we could to provide her with learning opportunities.

It was not our style to set goals for her or to have expectations with regard to her development. We had hopes, yes, but not expectations. I felt expectations could breed even more disappointment for not even Kari's doctors could accurately predict what she would be capable of accomplishing in the future. We took things one day at a time and we were able to take great pleasure from any accomplishment she made, no matter how small it was or how long it took to achieve. Each gain provided the motivation to work towards the next.

Intuitively we provided "what all children need". The "And then some" was the time and energy we spent trying everything that was suggested, or that suggested itself, to facilitate Kari's development. *It was* taking the time to follow through on

anything Kari, herself, initiated or showed an interest in and encouraging her efforts in any way we could. *It was* finding compromises, so that as she grew, we could continue to include her in all the activities the rest of the family enjoyed. *It was* the frustrating hours and hours we spent, before Blissymbols were introduced to Kari, trying to interpret her persistent communication attempts. *It was* the endless days sitting in waiting rooms — waiting for the many specialists and therapists who related to the multi aspects of Kari's disability. *It was* the frustration of filling out a million forms and answering a million questions over and over again, year after year, and the more intense frustration of not being allowed to see those precious charts. We felt that everyone in the entire facility was allowed to know more about our child than we were! *It was* the stress and time spent in keeping the essential electric wheelchairs and other aids and devices repaired and charged. *It was* standing by, supporting and comforting her through major surgeries — which gave us some insight into the emotional trauma and disempowerment we had been spared initially but which other parents, like Linda and Wayne, had suffered immediately following the birth of their baby. *It was* the struggle to keep a balance in our lives so that our other two children, who were very special to us also, received the time and attention they deserved. And last of all, for me, *it was* my own personal struggle to maintain an identity other than that of 'Kari's Mom'.

My Personal Challenge

It was this identity issue which gave me great difficulty when Kari took her first step toward a more independent living arrangement one year ago and moved from our family home into Participation House, a residence for the physically disabled. After twenty-seven years of fitting

my life around the almost constant, twenty-four hour responsibility of meeting Kari's needs, I was like a ship without a rudder and lacked a sense of direction or purpose. It was like learning to live in a different world. The adjustment has been made now and I am enjoying my new freedom, as well as my new relationship with Kari — one that is now similar to the relationship I have with our other adult daughter and son.

And Then Some

So far, the *and then some* has referred to the additional responsibilities assumed by parents of a child with disabilities and to the capabilities which Kari was fortunate to have. There is one more very important plus — all the bonuses and perks which Bob and I would never have experienced had we been led down a different path in life. We have been blessed with many wonderful, caring and supportive friends and professionals; doors opening to exciting situations and new technologies; pride and joy in Kari's accomplishments, magnified by what we knew she had to overcome to achieve them; and the greatest plus of all, her wonderful personality and infectious laughter which continue to brighten so many of our days.

Editor's Note

*An excellent reference for parents who want to read further about the feelings parents experience in raising a child with a disability is a book by E. T. McDonald called **Understand Those Feelings**. Based on his experience as the Director of the Speech and Hearing Clinic at the Pennsylvania State University, Dr. McDonald outlines a program he developed to help parents live more effectively with their feelings.*

References

Rush, WS. (1986). *Journey Out of Silence*. Lincoln, Nebraska: Media Productions & Marketing.

McDonald, E.T. (1973). *Understand Those Feelings*. Pittsburg: Stanwix House Inc. §

Word Prediction in MS DOS Land Part 2: Performance & Ease of Use Evaluation

JEFF HIGGINBOTHAM,
CAROLYN BAK, ANNE DRAZEK,
CATHY KELLY & KRISTIN WHITE

Jeff, Carolyn, Anne, Cathy and Kristin finish their presentation of several MS DOS-based word prediction programs by evaluating their performance and ease of use. In addition they will showcase some of the newest prediction software and provide some recommendations for MS DOS shareware.

Hello again! Last issue we began a review of five different word prediction programs which can be used on MS DOS (i.e., IBM style) computers —*Keywiz*, *Handiword*, *PAL*, *WriteAway* and *Access I-90*. In this installment, we will finish reviewing these programs by examining their *performance and ease of use*.

Performance

Two measures of word predictor performance were employed: the percent of keystrokes saved and the portion of the words accurately predicted by the word prediction program. In order to provide a fair, comparative analysis, we typed out the same text (footnote 1) using each word prediction program (footnote 2). As can be seen in Table 1, keystroke savings varied rather substantially with a low of 31% by *Handiword* to 47% by *Keywiz*. One of the problems with *Handiword* was that new words required additional keystrokes to store the word in the program's dictionary. The number of words covered by each predictor's dictionary also generally varied with key-

stroke savings. Interestingly, keystroke savings and vocabulary coverage were not necessarily related to dictionary size. As reported in the previous installment, *Handiword* employed a 3200 word dictionary compared to the dictionary sizes of *WriteAway* (750 words), and *Keywiz* (2200 words). Rather, how each predictor utilizes its dictionary appears to be more important to its performance than dictionary size.

Another aspect of word predictor performance noted during the review process was that *Handiword* and *PAL* displayed a perceptible delay (or flash) between each keypress and the appearance of a new prediction list. Reviewers consistently commented that this delay was distracting and irritating over time.

Ease of Learning and Use

Each word predictor was also examined in terms of its ease of operation, potential for permitting user error and how the information was provided to the user to facilitate learning and prevent problems from occurring. Setup and customization for each program appeared fairly straightforward. *Access I-90* and *WriteAway* provided easy to use menus designed to reduce confusion and error by displaying a limited number of choices at any one time. These menus could also be accessed directly from within the program. However, *WriteAway* was the only program to provide onscreen prompts for accessing the menu system. All other programs relied on the user to remember a typing sequence (*Keywiz*, *Access I-90*) or the name of a separate program application (*PAL*, *Handiword*), which we viewed as being potentially problematic to the consumer. *Keywiz* provided a relatively large number of control

options in each setup window (e.g., 21 for the keyboard controls). We felt this posed problems for locating desired controls, determining the status of a particular feature, and detecting the consequences of a keypress made in error. For example, on several occasions during the evaluation process, Jeff accidentally altered a keyboard setup feature without ever noticing that it had happened, until he began typing.

Documentation is a particularly important feature of these programs and one which is extremely difficult to design to meet consumer needs. We felt that both *Keywiz* and *WriteAway* excelled in this category. Both were comprehensive and clearly organized. However, only *Keywiz* provided documentation access to persons with physical disabilities via the computer screen. All other programs provided only hardcopy versions of their manuals. We found the *Access I-90* and *Handiword* manuals to be somewhat confusing and oriented to specialists rather than users. The *PAL* manual was simple to read and follow, but failed to include several important features of the program (e.g., selection of suffixes).

And the Winners are...

Weighing their features — performance, ease of use and cost across all prediction programs — we judged *WriteAway*, *Access I-90*, *Keywiz* and *PAL* to be overall high quality prediction programs, with each possessing a few problems noted in the review. *WriteAway* and *PAL* are clear winners if cost is a major consideration. Only *Handiword* appeared consistently weak when compared to the other programs, but its problems, noted in the review, should not prevent it from consideration.

Corrections

We thank Bob Follensbee, co-developer of *WriteAway* and Robert Basler, developer of *Access 1-90* for their comments on their products and on our review. Bob Follensbee indicated that only a QWERTY key arrangement is implemented for direct selection, but alphabetic and frequency optimized arrays are used for scanning. Also, keylatching and key repeat modification controls are incorporated into the program. Version 1.1 of *WriteAway* is now for sale (\$199). Robert Basler noted that *Access 1-90* does work on the original IBM PC and that it will work in a forty column mode. A new version of *Access 1-90*, (version 1.5) should be out by now.

Freeware and Shareware for IBM PCs

AccessDos. (From Trace Research and Development Center, University of Wisconsin-Madison, Madison, Wisconsin, 53706). In co-operation with IBM, Trace Center developed *AccessDos* which allows users to

customize many aspects of access including keylatching, response time, key repeats and keyboard emulation using augmentative communication aids. This is very high quality software and a *must* for adapted keyboarding!

NOCAPLOK.ZIP *Nocaplok* is a TSR that disables the Caps lock key. The state of the Caps lock key will be frozen in the state it was, when the TSR was installed.

KEYLOCK is a very stable, well tested TSR for MS DOS machines that converts left-shift, control and alt for one-handed or one-fingered typists.

NOKY14.ZIP This is version 1.4 of *NOKeys*, the TSR program that lets you input keyboard keys into most programs using just a mouse or trackball. This version adds a special option for monochrome display cards that makes the window and the mouse cursor easier to see.

Shareware

JOYKEY.ZIP is a DOS TSR program that simulates the keyboard with a joystick. It displays a window with a small keyboard on top of your application. You move its cursor to a key on the keyboard.

Footnotes:

1. The text used for this analysis was a 500 word writing sample produced by a 12th grade student. The text was originally obtained for research by Higginbotham(1992).

2. A word of warning! The performance results presented here should be viewed with some caution. A limited sample of text was employed and the performance of the various programs might differ with different texts. Also keystroke savings and vocabulary coverage relate only to the efficiency of these programs and do not address other important human factors such as features, adaptability and ease of use.

§

Table 1

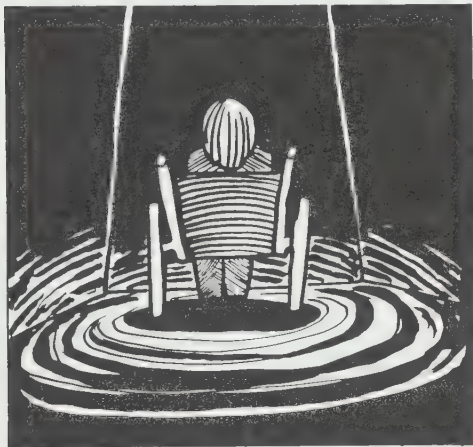
Performance Data¹ for the Word Prediction Programs

	Keystrokes Saved (%)	Words Predicted	Response Delay?	Ease of Use	Overall Rating
Acces 1-90	40%	87%	-	****	****
Handiword	31%	62%	+	**	**
KeyWiz	47%	92%	-	***2	****
PAL	44%	81%	+	***	****
WriteAway	37%	80%	-	****	****

1. The writing sample used for the performance comparison consisted of a 500 word 12th grade writing sample.
2. Previous versions of KeyWiz possessed noticeable response delays, but this problem appears to be fixed in the newest version.

Preventing Sexual Abuse in Nonverbal Persons

CHERYL BEDARD & LILLIAN BURKE



Cheryl Bedard, M.A. is a Psychometrist for the Ministry of Community & Social Services at Southwestern Regional Centre which serves individuals with developmental handicaps.

Lillian Burke has been involved, for the past several years, in the assessment and treatment of persons with developmentally handicapping conditions, a large percentage of whom are nonverbal.

The work of both Cheryl and Lillian has led them to sexuality issues and to implementing training programs for care givers.

As described in *Vulnerable*, the article by Susan Weber and Sachi Tamuri in the last issue of **Communicating Together**, persons with disabilities are at greater risk of sexual abuse than the non-handicapped, and this risk increases for those with communication impairments (Sobsey, 1988). This article will focus on the social attitudes that increase persons' vulnerability to abuse, and offer some suggestions regarding appropriate intervention to empower the individual.

Limited Access to Information

Our society, in general, has difficulty in providing its children with accurate sexuality information (Rowe and Savage, 1987). Typically, it is shrouded in secrecy and often is presented as wrong or dirty. Caregivers often hold the belief that full information will promote sexual activity.

This attitude is reflected in the treatment of sexuality issues for the developmentally handicapped population, for in the eyes of society they remain as children (Rowe and Savage, 1987). It is further perpetuated by myths regarding the handicapped person's lack of sexuality, high level of fertility or potential for deviant sexual behaviour. The denial of sexuality is expressed in the hesitancy of caregivers to provide sexuality information, and has effects on both the ability of persons to express themselves as sexual beings as well as their ability to protect themselves against sexual abuse.

Importance of Education

Both sex education and positive sexuality training should be provided prior to abuse prevention training, so that the person does not interpret all touching in a negative manner. Differences in cultural and societal background should be considered, as well as the person's present living situation. Lastly and perhaps most importantly, the possibility of prior or present victimization must be taken into account. Caregivers must be prepared to help the person to express feelings related to past experiences.

Many authors have developed intervention programs for persons with handicaps emphasizing that information should be given at the level of the individual (Saroi, 1989).

Persons with a severe developmental delay may need information presented in a concrete and simple manner. However, few authors of such programs have addressed the needs of nonverbal persons and the use of AAC systems. In order for nonverbal children or adults to report abuse, they must have symbols describing relationships (who the person was), emotions (how they feel) and what happened (body parts, etc.).

Once introduction to an AAC system begins, many caregivers seem to find it difficult to use the system in a manner that is beyond the expression of basic wants and needs, e.g., eating. The nonverbal person with a developmental delay may be exposed to vocabulary of limited functional use in social or therapeutic contexts. Further, it has been our experience that caregivers rarely give these individuals sexuality information or the vocabulary required to discuss such issues for the same reasons that apply to verbal persons with handicaps.

Sexuality resource groups for caregivers are less common than are client-directed programs. Instructors in this realm need to be both knowledgeable and comfortable with the material. Information and support must be provided without attempting to change morals or values.

Training Considerations

Some issues presented to caregivers will be the same for both parents and professionals. For example, birth control information and safety issues can be presented in a fairly concrete fashion. The presentation to either type of caregiver group can be similar. The goal is to provide the facts, to enhance comfort in presenting the issues and to make available the required AAC systems

and visual aids. In contrast, a discussion of the need for privacy in order to engage in a sexual relationship will need to be addressed very differently. Residential caregivers may be concerned with ensuring that the individuals who engage in sexual activities on the premises are consenting adults. Conversely, parents may have rules prohibiting their adult children from engaging in sexual activities within the family home. Parents may then be struggling with the need to maintain house rules while allowing their offspring to meet their sexual needs. The group facilitator must provide support without being judgmental, encouraging group members to discuss the issues and share in finding acceptable solutions.

Research Findings

Results of research indicate that 80% of all handicapped persons are victims of sexual abuse at some point in their lives (Senn, 1988). Those who receive sexuality information are victimized much less frequently than those who have not been provided with the necessary education. Sobsey and Mansell (1990) remind us that even those who have received sex education and who try to prevent abuse may still be victimized. As with other victims of assault, these individuals have the right to appropriate treatment to reduce the psychological effects of the abuse.

The vulnerability of persons is known to be greater if they cannot report an abusive incident. Sobsey and Mansell (1990) have demonstrated that the ability to communicate decreases the perception that a person is vulnerable and therefore the risk of an abuse occurring. Further, communication impairment decreases the likelihood that the offender will successfully be prosecuted (Sobsey, 1988). Too often the persons with developmental handicaps with whom we work are

vulnerable because of both deficits being addressed in this paper: lack of sexuality information and lack of a functional AAC system. The following example may highlight our concerns.

Increasing the Vulnerability

A nonverbal child was approaching adolescence. This child had begun to learn vocabulary from a variety of symbol sets at around five years old, but no AAC system had been developed in an ongoing and functional manner. Therefore, this child had limited ability to communicate, although cognitive potential was apparent. The child was involved in a group which was to receive a streetproofing program. The caregiver requested that the child be removed when body parts were discussed for fear the knowledge that the child had private body parts might encourage exploration of them. A child such as this who cannot report an abuse is liable to be victimized repeatedly. If abuse occurred, the child could neither express what had happened nor respond to questions due to an inability to understand the terms which would be used. Attempts to explain the vulnerability of the child to the caregiver were futile. Victimization can begin at a very early age. If the victimization is not reported, it could continue for 5 to 15 years (Ryerson, 1981). However, for people with developmental handicaps, there is a

tendency for the victimization to continue into adulthood because they continue to reside in settings where they are dependent on caregivers or relatives (Ryerson, 1981). When a person is raised or lives in a support service system, he or she is often taught to conform and to obey caregivers without question. Does this enhance vulnerability? Sexual offenders are frequently caregivers or relatives of handicapped persons (Ryerson, 1981).

Reducing the Vulnerability

To prevent increased victimization, it is necessary to educate children, adolescents, adults, parents and professionals about sexual abuse. Some programs address the possible victim. For example, there is the videotape "Feelings Yes, Feelings No" (National Film Board of Canada, 1989) which is a film program for young children on sexual assault prevention. Other programs seek to educate parents and/or other caregivers, before attempting to help potential or present victims. Different modes of presenting the information have been used such as theatre groups, police agencies, storybooks, colouring books, films, campaigns with famous

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people and educational materials.

There are only a few programs available for individuals with developmental and/or physical handicaps who utilize AAC. The number of resources is growing but may be difficult to find. Many of the programs that are available can be adapted for an individual's needs. The "Life Facts 2: Sexual Abuse Prevention" (Cowardin and Stanfield, 1989) curriculum is a tool to teach both the preventive and reactive aspects of sexual exploitation. The materials are designed to be suitable for mildly and moderately handicapped groups. As well, the "Life Facts: Trust and Personal Safety" program helps to prevent people from being vulnerable to financial, social, physical and sexual exploitation. Both of these programs are available from the James Stanfield Publishing Company (the complete address is at the end of the article). Szroi and Carey's (1989) curriculum uses anatomically correct dolls and role play to teach appropriate social interactions and how to handle unwanted sexual advances. The authors indicate the use of sign language for those who communicate in this medium. They are one of the few to address this issue.

The Goal

The goal of most of these programs is assault prevention and empowerment. The curriculum often entails sex education, self protection, assertiveness training, help-seeking behaviour, sexual abuse prevention, choice-making and personal rights education.

Unless properly educated, many people remain open to exploitation. Numerous victims might have been spared traumatization if a caring person had provided some simple pieces of information. As well, denying a person access to sex education may increase the risk of pregnancy, sexually transmitted diseases and potential abuse by those who will exploit an individual's lack of

knowledge about sexuality (Sobsey and Mansell, 1990).

For those who have been victimized, empowerment and immediate treatment are essential aspects of their recovery and future abuse prevention. Previously abused children are at high risk for recurrent abuse (Finkelhor, 1986). However, providing personal empowerment and sex education can help break the cycle.

Of the treatment programs that do exist, few address the specific needs of people who use AAC and have a developmental and/or physical handicap. Not only are the services often inadequate but they are often very difficult to obtain. Many victims have not as yet received treatment. We are now seeing people that were abused 20-30 years ago. They have had difficulty dealing with this on their own for all these years.

Being the recipient of abuse can be a very traumatic experience. As Jenny, Sutherland and Sandahl (1986) have reported, research has shown that such an experience is associated with depression, low self-esteem, suicide attempts, school failure, regressive behaviour, drug and alcohol abuse, running away, sexual promiscuity, prostitution, sexual dysfunction, criminal behaviour, multiple personality and further sexual assault. We must attempt to prevent this through education. Individuals with a disability are defenceless not because of their handicap, but because of their lack of information about sexuality and sexual abuse. (Ryerson, 1981).

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Independence '92 or The Revolution is Now!

Geb Verburg

Down With the Oppressors!

I have always thought that on the political spectrum I fitted somewhere between left-of-centre and radical. Similarly, in the world of AAC and rehabilitation I tend to locate myself just to the left of the professionals and closer to the role of a consumer advocate. In other words I considered myself a consumer's ally, a person of the people, a revolutionary who is temporarily earning a living. These self-gratifying perceptions were rudely shattered at a conference I attended last April in the beautiful Canadian city of Vancouver.

I have been to some fifty AAC and rehabilitation conferences and all of them have been organized and primarily attended by rehab/AAC professionals. Most of these conferences were of the scientific or at least soft-scientific variety. That means that learned persons or professionals talk to other learned persons or professionals.

Independence '92 was very different. Independence '92 was a conference with many faces and many messages. On the surface, it was one of the largest gatherings I have witnessed in which people with disabilities attended along with professionals, government officials and business representatives. The overt message, very ably stated by the conference chair, Rick Hansen, was that the collaboration of persons with disabilities, governments and business can create an environment in which independence becomes possible and effective.

Another, somewhat deeper, yet very forcefully presented message

was a political one that asserted the right and the wish of persons with disabilities to take control of their lives, their devices, and the policies pertaining to their existence.

At Independence '92 I came to perceive professionals as highly skilled and motivated people who, with the best of intentions, "do things for" persons with disabilities. And the many consumers (approximately 1,500) who attended Independence '92 left little doubt about their displeasure at "having things done for them" by professionals, or government officials, no matter how well-meaning.

The level of anger, the sense of frustration, and the powerful feelings expressed at this conference can be gleaned from the following quotes recorded during some of the sessions.

"Liberation must come from the oppressed, it cannot come from the oppressor." Tanis Doe quoting Paolo Freire in the opening session entitled "Liberation and Visions."

"The time for words and lip service is over . . . It is disabled people who have to change our world." Rachel Hurst.

"Every step we take on the road to progress will be the result of the 'organized disabled'." There will be *"No full participation without employment."* Joshua Malinga.

The sense of anger was so strong that representatives of traditional support agencies felt acutely uncomfortable, were snubbed informally, and many professional who presented at sessions saw their audiences dwindle during the course of a too traditional presentation.

Power to the Oppressed

Needless to say, I was thoroughly shocked for about half a day (to be

honest, I occasionally cringed afterwards). Eventually however, as a consequence of my position as a researcher or marginal professional I felt less threatened than other people and I was able to see the beauty of the scene. Here were over 3,000 people, half of them with disabilities of all kinds, from over 135 countries. There were many representatives from African countries, from Japan and other cross-Pacific neighbours, a fair representation from South America and Europe, and far fewer people from the States than I would have expected. All the main disability groups were represented. And I believe that about ten percent of the leadership of all major disability movements of Canada, as well as the top representatives of Disabled Persons International (DPI) organizations were present — a powerful group and certainly not your average meeting.

When I finally stopped feeling personally attacked, I had the best time of my life. I felt like I was physically transported back in time by about a quarter century. I was on the barricades again; the rhetoric at Independence '92 was similar to that of the (Amsterdam) student revolutionaries and hippies of the sixties. The mood was definitely that of an imminent revolution, a rallying cry for change. The anger and frustration with the intolerably high unemployment of persons with disabilities, with the pervasive poverty, the paternalism, the oppression, was voiced or signed by strong people, by independent people, by people who clearly showed that they can and will represent themselves, govern themselves, speak and decide for themselves. Here were people who had taken control, taken power.

And all of a sudden the concept of "empowerment" rang hollow. If

the oppressor cannot liberate the oppressed than she or he also cannot empower the disempowered. As Justin Dart (1992) said: "We of the disability community will lead the revolution for our empowerment, or that revolution will never occur."

So what about the professional? What about those of us who are working in AAC or rehabilitation or research? And what about nonspeaking children? Can *we*, can *they* be part of this revolution?

What about nonspeaking children?

Children with physical and communication disabilities are cut off from many things. They are cut off from the many normal learning opportunities that able-bodied children walk and talk their way into; I have written about this in earlier columns. They are also cut off from the attitudes, the consciousness, the revolutions that are inspiring the adult community.

How will nonspeaking children and young adults learn about the new consciousness — the new power that is emerging? How will they realize that they will be expected to take their place in the work force, on the advisory councils and on governing councils? Who will tell them? Who will teach them? How will they learn if we the parents, professionals, researchers do not expect them to take those places, to get jobs - to create jobs, if necessary? Are we AAC parents, AAC professionals, AAC researchers ready for this scenario? Are we part of this revolution or are we still the oppressors?

It sounds awful, doesn't it? "Oppressor!" All we're trying to do is facilitate, train, enable, empower, give children a chance to communicate. True, and from our point of view that is what professionals were trained to do and are being paid to do. And all of a sudden the clients, our customers, change the criteria on us. They (our customers) do not

necessarily want to walk like us, talk like us, think like us. They certainly do not want us to tell them what is best for them unilaterally. *The goal of rehabilitation itself has changed.* The adults are saying, "Why did you waste my time with therapy when you could have been training me for a job, to live independently, to balance my budget? Why did you not accept me as I was and work *with me* towards what I wanted to become rather than aspire to rehabilitate me in your image?" These I believe are the real messages that are coming from the persons with disabilities. And it's only from them that the ideas have sufficient validity and force so that we (the other part of the us) will listen.

Justin Dart, Chairman of the United States President's Committee on Employment of People with Disabilities, spoke at Independence '92, and earlier to a Standing Committee in Ottawa. From the latter presentation come the following excerpts:

"Disability is not a matter of 'them and us'. It is just 'us'." This 'us' for Dart means everyone, people with disabilities and people who do not have disabilities and he continues; "In a rational society there will be no distinct disability policy, only public policy which empowers all people. In a rational society the government agency which I head will not exist. . . . I am talking about fundamental changes in attitudes and systems, massive reallocations of the human and economic resources of modern democracy from conspicuous consumption and paternalism to empowerment and productive quality of life." (Dart, 1992).

What about the professionals?

For AAC professionals this means that we have to listen harder and that our listening must take a detour. Our customers are the least vocal of the

rehabilitation world, the least powerful. Many of our customers are children cut off from the larger movements in the field. Of course we have to continue to listen to our customers (clients) but we must also keep an ear to the ground for the ideas gaining strength in the wider world of people with disabilities. We must adjust our approach to the demands and expectations that govern that world.

We may have to redefine our goals and I believe that many of you have done so already or are actively looking to do just that. As Karin Paulsson, a psychologist colleague of mine, has for the past ten years or so been emphasizing: All therapy, all rehabilitation intervention carries a direct message to the child that says: "*You are not good enough the way you are. We will fix you.*" That is not how we should approach our jobs. We have to begin by accepting the children as they are for what they are and for what they want to become. Then, and only then, can we offer our expertise to help them achieve what they're after or help them find out where they want to go.

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INDEPENDENCE '92 Congress and Exposition, Vancouver, British Columbia, Canada, April 22-25, 1992.

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Finding Her Own Way

GABRIELA RAQUEL BRIMMER
DLUGACZ



Gabriela Raquel Brimmer Dlugacz was born in Mexico, D.F. on September 12, 1947 with cerebral palsy that profoundly limited her physical abilities including her ability to speak. Her mother was Sara Dlugacz and her father was Miquel Brimmer. "Gaby" spent much of her time with her faithful Nanny, Florencia, who accompanied her to most places she went and who still lives with her. Gaby spent several years in a school for handicapped youngsters. She was not content with what she was learning at the school however. With the help of her parents, Florencia, an indomitable spirit, and her left foot which she used to type, Gaby applied for and eventually successfully sat the qualifying exams to enter into the regular school system. This was something that until then had been almost unheard of for someone as disabled as Gaby. Assisted by Florencia, Gaby eventually finished college and became a successful writer and mother. A movie about her life, released in 1986, is one of the most powerful and sensitive treatments of disability ever filmed.

First of all, I would like to thank Dr. Peter Lindsay for inviting me to participate in the magazine, **Communicating Together** and to share my experiences following the point reached in the movie, *Gaby — A True Story*. In the movie, we tried to present the problems experienced by people with physical limitations. We, as disabled people, are still being discriminated against in many countries and societies despite the advances of science and technology. I realized this strongly when I was invited by Associations of Disabled People to Puerto Rico and Italy after the movie was released. As in my country, disabled people in these countries are restricted to their working places or to supported houses, despite laws that are supposed to protect them. Also, as in my homeland, these countries have several facilities which attempt to integrate disabled people into everyday life. Although they have personal assistance from volunteers that help them with their day-to-day needs, there is no communication among people with disabilities. What is worst, there is no will to look for alternatives for a more normal life.

After the the movie began to be shown, I received several letters from people with physical disabilities asking for advice on problems in their lives. Truly, I find it is not easy to give advice. Each case is different and each person has to find his or her own way depending on their circumstances. This attitude may seems to be a bit selfish. But there are no rules and no easy solutions in a society that is becoming more complex and individualistic everyday. This is

what life has taught me.

The importance of love

It is very important for people with physical disabilities to live the experience of love. Love is one of the most beautiful ways for any human being to communicate. I understand the fear caused on the family when the disabled person is in love and has sexual relations with his or her partner. Even so, I would rather love than feel myself empty. After the movie, I dedicated more time to my daughter, Alma, who was ten years old at that time. I think that the education of children of parents with disabilities is very difficult, because it is not direct. It is always necessary for another person to help him or her to communicate with his or her child. Often there are problems due to different opinions.

Communication with my daughter, Alma, has had great difficulties for she is an impatient girl like any other child. I understand that it is not easy for her to sit and read my communication to her through using the alphabet. With time, Alma and I have reached a close relationship based on living together and my love for her. Now, she is fourteen, the age of not knowing what she wants or whether she is a girl or an adolescent. She like dogs and she would love to have the house full of them. She wants to study to be a veterinarian. I wish and hope life gives her all that she wants.

The rights of people with motor impairments

After the release of the film, I received many gestures of affection from people all over Mexico. In addition, I have taken on a big job. Five years ago, I organized an Association with People with Disabilities as a self help group to

defend our rights. The name of the association is ADEPAM, I.A.P. or "Association for the Rights of People with Motor Disabilities", The I.A.P. Private Assistance Institution is supported by donations. This association is in contact with other associations that have the same goals as we have. This takes my time and my strengths from what I truly enjoy - writing poetry.

The Gabriela not revealed in the film

Sometimes I feel that the film did not give me peace of mind, but rather a great responsibility. I wrote the film's script in order to express my identity, my existence, my continuation as Gabriela. The film did not adequately portray one aspect of my personality - that of rebelling against the things I consider unfair. The following poem which I wrote three years ago will show you more of who

Address of Gaby's Organization

The address of the organization Gabby founded - *The Association of the Rights of Persons with Physical Disabilities* is:

Avenida Dos No. 290
Col. San Pedro de los Pinos
C.P. 03800
Mexico, D.F.
Phone 611-55-65

Special Thanks

We want to express a special thanks to Paula Velaochaga who translated the material sent to us by Gaby. Paula, who is also from South America, had not met Gaby before. Through Gaby's poetry, however, Pauls felt she had encountered a kindred spirit.

§

*Latin America, Le Tub
the Tub of blood and shit
and of nuclear waste wrapped in
long tubes and deep excavations,
misleading the people who
ignore what the nuclear engineers
and their accomplices, the government, knows.*

*Latin America, you hurt me
from the bottom of my blood;
you hurt me, you hurt me, deep in my body systems
because you are mine, my motherland,
the great wounded land, the mother,
the earth, the sky, the wind that
passes by the pyramids and sings, whistles,
moves through the ruins
and the skyscrapers and buildings d
estroyed by earthquakes and inner wars.*

*Latin America, covered in blood now,
and for centuries by diverse imperialists
that take you by force,
raping you like a woman,
then killing you with starvation, with thirst,
or just leaving you empty, empty.*

*Latin America, let me fill
your wounds with words; I know you are
defeated, tired, sad, distressed,
Your own children sell you to
the highest bidder in a big auction.
"Who pays more?" is heard in Mexico,
Brazil, Venezuela, Chile,
Colombia, Panama, Argentina,
"Who pays more for your raw material?"*

*Latin America, now you do not care,
they rape you for the umpteenth time
Your nice body, beautiful with its
jungles, deserts, tropics,
glaciers that ask nothing from anyone....*

*You let everyone touch you
ashamed of your involuntary nudity,
and sometimes you spit saliva of fire
and terror from your volcanoes' craters...*

*You tremble, Latin America
very often
It seems as if you feel like
disappearing
before a new imposter
rapes you.*

*But, Poor you!
Beautiful woman and mother, poor you
If one day trying to escape from us,
you disappear leaving us without
a motherland, with empty hands
without a land where
to put our damned trace.*

*Latin America, don't die,
don't leave us alone,
don't abandon us, don't give up on us, mother!*

*If you disappoint us, is it because
we disappointed you?
I say this for everybody.*

*The innocents, the guilty, the honest people,
the dishonest people, the guerilla fighters,
the invaders, civilians, the religious.
We are all guilty of
abusing you.*

AND WE ALL HAVE THE LAST WORD.

*Silence, silence
please ladies and gentlemen...
Silence, for the great motherland is weeping.*

Gabriela Brimmer

Parenting in the Fifties and Sixties

JOSEPH CREECH



Joseph Creech is a Southern Baptist minister and a registered nurse. His wife, Margaret, is a full-time pastor's wife, housewife and mother. They have two sons, Rick who is the focus of this article and Avis, who is 14 years younger than Rick.

At present, Reverend Creech is pastor of Cedar Grove Baptist Church in Wilson, N.C. He also works as a nurse at a maximum security penal institution, known as Central Prison, in Raleigh, N.C. His area of work is mental health. They live on a portion of the farm on which Reverend Creech grew up near Selma, N.C.

The advance of technology during the past fifteen years has had a tremendous impact in the lives of thousands of people. This is especially true for those with speech impairments. My wife and I wish to share with the readers of **Communicating Together** some of our experiences and frustrations of being the parents of a severely speech-impaired son, before this "Age of Technology". Our son, Rick Creech, was born in 1954.

Before talking about problems, frustrations and anxieties, we wish to share with you that there were many happy experiences for us. Many people thought, "Oh, My God, you have a physically limited child. Your life must be miserable, difficult, and unhappy. I feel sorry for you." We would like to express to everyone that there has been joy, laughter, happiness and fulfilment in our home.

As parents, we have always sought to emphasize the positives not the negatives in our family. We have had and continue to have dreams, expectations and faith for the future in the life of our physically limited son. We do not deny that often we have had to reprioritize our expectations and dreams.

When Rick was born, we were not given a diagnosis - not even a guess about why he was having a problem. When he was approximately one year old, the term cerebral palsy became a very important part of our vocabulary. Until then, we had only been told that he had received brain damage at birth and that we would just have to wait to know the amount of damage and the areas of involvement.

We realized that Rick would not be able to walk early in his life. We also knew, at a very early age, that he was not mentally retarded. My wife and I felt that mobility was important for any child. We found a special walker in the Sears Catalogue that would adjust to children aged two through twelve. This walker had ball-bearing wheels and an adjustable tricycle seat in the middle which enabled his feet to touch the floor. Rick was two at this time and we purchased the walker even though we were told by several people that we were wasting time and money because he would not be able to use it. However, this proved to be one of the best investments we ever made for him. With the walker, Rick could take himself all over the house.

Needless to say, he sometimes got into mischief, too. Sometime later we had a tray built to attach to the walker; this gave him space to play and to look at books. There were times when we were constantly picking up things from the floor to place back on the tray for him but he was busy and happy.

When Rick was about three-and-a-half years old, we learned about the North Carolina Cerebral Palsy Hospital, now the Lennox Baker Children's Hospital, in Durham, N.C. We wrote them seeking information and giving them information concerning Rick. We were given an appointment to take him for an evaluation; after testing, the decision was made to accept Rick as a resident of the Hospital. Rick was excited and so were we; however, we soon learned that the decision to take him and leave him in the care of total strangers was the hardest thing we ever did. We were only twenty years old and with just high school educations; thus we had little experience in life when he was born. We did know that we wanted to be good parents and having no experience with any other children, we did what we thought normal. We determined to give Rick every opportunity in life that was possible for us. Leaving him at the C.P. Hospital was a terrible experience for all of us. Rick had never spent a night away from us, so the thought of taking him back home with us entered our minds. However, the overbearing thought prevailed - to remain at the hospital was one of those opportunities we desired for him.

We visited Rick every Sunday afternoon for two-and-one-half years, taking him special food, treats and gifts. My wife wrote and mailed him a card every day that he was there. When we arrived each Sunday for our visit, Rick would be crying. When we left, he would cry again. This continued for approximately three months. It is impossible to

express how our hearts ached during that time.

While at the hospital, he received daily speech therapy, physical therapy, occupational therapy and kindergarten schooling. He received braces and crutches and learned to take a few steps. After going through hours of physical and speech therapy, we knew that walking would never be an option for Rick. Neither would the ability to speak be possible for him. Those two abilities were primary in Rick's and our minds when he entered the hospital. However, we realized an alternative would have to be found. He learned to use a typewriter by a harness attached to his left arm and a brace with a device similar to "Captain Hook's crook" fastened to his hand. This allowed him to somewhat control the spastic movements of his arm. Finally, at the age of six, the physician there told Rick that he would not be able to walk and that his accomplishments in life would be with his mind.

Believing that he must learn to read, we searched for ways to teach him. There were no special schools in the area in which we lived and at that time public schools wouldn't even try to teach children like Rick. We were extremely frustrated to say the least. The Cerebral Palsy Hospital helped us by giving information about the Calvert Correspondence School in Baltimore, Maryland. This was the school we used to teach Rick. For several years my wife taught him each grade using an organized system of study each day. It was a very responsible and disciplined system and extremely thorough. Friends, relatives and others would often ask, "Why are you trying to teach him? He will never be able to do anything." Our answer was always, "If he never does anything but watch T.V., he will enjoy it more with an education." We now know

that even then, God was preparing Rick for a future that would enhance not only his own life but that of many others.

Our efforts were not enough to keep Rick's social development from becoming stagnated as he grew older. Although we always took Rick everywhere we went, we knew that was not enough. As a teenager, he was always on the outside of any group. The small, cute child had become an adolescent who didn't fit anywhere. My being a pastor did keep him getting out of his room and the house, and going to church and church-related functions. We offered what we could, but it wasn't enough. Rick began taking his alphabet board everywhere he went and would communicate with anyone who would spend time with him. However, it took more patience than

most people had. He started reading voraciously and using an electric typewriter to express his thoughts. He could type by using a headpointer. Reading and writing his thoughts was the way he spent most of his time. His social development would come later while he attended college.

As his parents we always did for Rick what we thought was in his best interest no matter what anyone said or did. Sometimes, our decisions were not the best. We learned from them, however and in retrospect, we believe most of them were good decisions. We always expected and demanded that Rick give all that he was capable of giving. We felt it necessary to impress upon him that second best was not acceptable. This continues to be our belief today, for anyone, with or without limitations.

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Parents and Symbols: Charting the Language Pathway Together

SHIRLEY MCNAUGHTON

It is particularly fitting that we look again at language in this issue of **Communicating Together** which has parenting as its theme. As a way of thinking about the roles of parents and symbols within the language development of children, I am borrowing an idea presented by Daniel Keating in his writing about cognitive development. Keating stresses the importance of *patterns of thinking* upon the ways in which children develop. He calls these patterns "habits of mind" and argues convincingly that children develop competencies through acquiring habits of mind which allow them to be successful in various tasks. He proposes that we think carefully about *charting pathways to the development of expertise*. This requires (a) consideration of the *context* and the *content* of the activities which support the development of children's habits of mind and (b) recognition that learning is an integrated cognitive activity.

I have found it helpful to apply Keating's ideas to the language learning of children who use symbols for communication. As we chart their pathways to the development of language expertise, we can consider both parents and symbols as providers of content and context and we are reminded of how important it is to integrate symbol learning with all aspects of development. To chart a stimulating pathway of learning, the child must have many rich experiences. *Parents* can arrange the child's life and language opportunities; *symbols* should afford a full language capability to the child and

an instructional guide to his or her parents.

The Many Dimensions of Language

What are the skills of language to which pathways must be charted? Catherine Snow at Harvard University has identified several dimensions of language through her study of young children's language development. Her ideas have been applied to the assessment of individuals who use augmentative and alternative communication (AAC) by Nicola Nelson of Western Michigan University. The following are the domains of language described by Snow (1991) and Nelson (1992). First there are four rule systems related to linguistic structure - *phonology* (the sound system of language); *lexicon* (the words of language and their relationships); *syntax* (the sentence structure of language); and *morphology* (the smallest meaningful units of language). Then there are three rule systems related to language use: *speech acts* (the things a person does with language); *conversation* (the process of interacting with another persons through language); and *discourse* (ways of constructing and organizing text in oral and written language).

Nelson looks at all of the above aspects of language when she is considering a child's abilities. To integrate Snow's and Nelson's view of language with the ideas of Keating, we can consider the domains of language to be strands *within the pathway to the development of language expertise*. Each strand is important at different times along the pathway and contributes in different ways to the *habits of mind* which will support specific language skills. When we are evalu-

ating a graphic communication system or set, we need to consider *all* the above language domains to see how well the graphics can support the child's total language development.

Lexicon

We have already discussed *lexicon*, referring to it as *vocabulary* in the March, 1992, SymbolTalk. It is important that AAC users have, or can construct, the symbols for all of the needed words that can be anticipated. This is easiest when children have a system with rules by which the vocabulary items are related to each other.

Morphology

It helps if the child can learn the rules which indicate how the parts of each symbol fit together. It is in this way that *morphology* can support the development of a growing *lexicon* (vocabulary). Children should be able to use their knowledge of how the parts of their symbols relate to each other to create new symbols to meet unexpected vocabulary needs. Of course the best system in which rules can be used to create new words is print. Children who can spell are very fortunate. Every word is available to them.

For those who cannot spell, however, other graphics must be used for communication. The graphic system which comes closest to print in providing symbol units which have rules governing the relationships of one unit to another is Blissymbolics. With Bliss, the symbol parts are easily drawn and they can be combined and recombined to form new symbols. With Bliss, children spell with the Blissymbol meaning parts. Symbols like Picsyms and Dynasyms for which there are rules as to how new symbols can be created by those

supporting the child, offer the generation of symbols as well. Only print and Bliss, however, allow children *themselves* to use symbol components to produce new symbols.

Phonology

In the area of *phonology*, all symbol systems other than print are found lacking. Only print is based on a unit-to-sound association. Often there are exceptions to the rules, but we are always using the sounds the letters make when we identify and create words in print. Rebus symbols use sounds in a limited way by applying (i) initial sounds as in the combining of the letter “c” with the picture of an old man for *cold*, and (ii) the sounds of entire words as in the Rebus symbol for both *I* and *eye* in which the picture of an eye is used. Minsymbols™ as used on the Touch Talker™, Light Talker* and Liberator™ sometimes behave like rebus symbols and have more than one meaning associated with a particular word - e.g. the future tense of the verb *to be*, “*will*” is associated with a picture of William Shakespeare. It is important to observe children carefully to determine whether or not they can take advantage of sound-referenced rules in their early use of symbols.

Syntax

Syntax is another very important dimension of language which should be investigated when considering a symbol system or set. Do the symbols have ways of representing the grammatical aspects of language? This involves being able to portray the parts of speech in all their forms.

Speech Acts, Conversation and Discourse

Snow and Nelson identify the rules associated with *speech acts*, *conversation* and *discourse* as important aspects of language for the young child. Do the symbols allow children to participate in such *speech acts* as making requests, commenting,

confirming, denying, providing information? Do the symbols support children’s involvement in the give-and-take of *conversation* — initiating and responding, asking for clarification when messages are not clear, changing, discontinuing or prolonging the subject as they wish, and getting their fair share of turns? And most important of all when it comes to the later learning of *reading* (which will be the topic for the September SymbolTalk) — do the symbols afford children’s participation in different forms of *discourse*?

Children need to use symbols for communication in both *narrative* and *expository* forms of *discourse*. These forms are more formal, requiring longer and more complicated sentence forms. When they are used the child does not have the regular feedback which he or she receives within conversational discourse. Having symbols which allow the child to become involved in story telling and in expository discourse, in which the child selects and transmits relevant information to listeners (as in show-and-tell time in Kindergarten) is an important requirement when selecting a symbol system.

Back to Parents and Symbols

Parents (and instructors) who wish to support the development of the above domains of language must have high expectations of the symbols used by their child. It is not enough for the child to hear others engaged in all the above language activities, although it is certainly important for the child to have an environment that is rich in listening opportunities. If we compare language learning to that of learning to play the piano, we can readily see how inadequate it would be for the child to listen to the piano playing of others and hear about what he or she *should* do, but never have any opportunity for “hands-on” experience. Symbols should provide the child with the learning that comes with doing something for himself or herself.

Interaction for Integrated Learning

Another challenge for parents of children who are unable to speak comes from the nature of language learning itself. Speaking children alert their parents to their language needs and the topics that interest them by *what they say*. Their language develops through their many hours of talking with their parents and others close to them. Sensitive parents respond and offer the learning that is appropriate to the child.

When children are unable to speak, their symbols must allow them to demonstrate what language capabilities they have and what they would like to talk about. Symbols that support interaction that is fully shared by both the child and the parent are essential.

The Challenge for Parents of AAC Users

Using Keating’s terminology, children need to develop *habits of mind* that support the development of language expertise. For young children who use an AAC system, the pathway must be charted carefully, considering all of the language dimensions identified by Snow. Parents should participate in planning and in ensuring that their child will follow the richest language learning pathway possible. The goal should be nothing less than a symbol system for full language development.

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Gran-For-Line Association for Community Living
P.O. Box 1090
GRAND BANK, NEWFOUNDLAND, A0E 1W0

RE: *Vulnerable* by Susan Webber & Sachi Tamura.

Dear Co-editors

I am writing to you first of all in praise of the March 1992 issue of **Communicating Together**. The issue of sexuality has long been ignored or swept under the carpet. Why do *they* need to know about *THAT*.

All the articles in the issue are interesting and informative. I was especially pleased to see the article *Vulnerable*. I was however surprised that no mention was made of the ARCH (*Advocacy Resource Centre for the Handicapped*) publication entitled **Responding to the Abuse of People with Disabilities**, (1990).

This ARCH publication presents an overview of various types of abuse, definitions of disabled, and the extent to which the law represents victims of abuse. It is not an in-depth publication. It does however provide a solid foundation for individuals who are not knowledgeable in legal terminology, or catch phrases used by professionals in the field of services to the disabled.

If interested (I apologize if you are already aware of the publication) in obtaining a copy, they are available at the following address:

ARCH
40 Orchard View Blvd., Suite 255
Toronto, Ont Canada
M4R 1B9

Thank you again for an informative issue

Respectfully,

Maureen Bethel
Pre-employment & Placement Co-ordinator
Gran-For-Line Association for Community Living

1. **Editors Note:** The Editors will be happy to publish the details of where the CALL Centre survey can be obtained in the September issue of **Communicating Together**.

Dear Mrs. McNaughton,

You are quite welcome to use the quote from **The Trouble Bush** as it appears in your publication. **Communicating Together**. I am very pleased to know the book is still being read since it has been out of print for quite a few years. My husband had a productive and fulfilling life and through his writing was able to share it with many others.

With best wishes for the success of your magazine,

Sincerely,
Starling W Meirs

Dear Editors,

RE: *Word Prediction in MSDOS* by Jeff Higginbotham and colleagues in **Communicating Together**, Vol. 10 No. 1/March 1992

We were very interested in the above mentioned article as this is the area that the CALL Centre has also been studying. Please, if it is possible before the next issue, when I believe a 'sequel' to the article will be published, could you consider including the following points?

1 ERRATUM

Jeff Higginbotham refers twice to the work of Alan Newell's team on PAL as taking place at the University of Edinburgh, Scotland. This is a mistake — Professor Newell and his team actually work at the Microcomputer Centre, University of Dundee, Scotland.

2. NEW PUBLICATION

The CALL Centre, University of Edinburgh has recently completed a very comprehensive survey of all the word prediction systems currently available in the UK that might be useful to people with disabilities of various sorts, particularly with regard to educational contexts. This is currently in press and will be available after August 1992. We think it will be of interest to your readers to know of the book, and would be grateful if you would publish an advance notice of its publication.¹ A suitable place obviously would be near the second part of Jeff Higginbotham's article. I am sending details of the publication on an attached paper,

Sally Miller
Joint Coordinator, CALL Centre

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